

**Clinical Commissioning Group Governing Body**  
**Paper Summary Sheet**  
**Date of Meeting: 20 May 2014**

For: PUBLIC session  PRIVATE Session

For: Decision  Discussion  Noting

<b>Agenda Item and title:</b>	<b>GOV/14/05/18</b> Wiltshire Dementia Strategy Update
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<b>Executive summary:</b>	The purpose of this item is to present an update on the progress of the Wiltshire dementia strategy consultation process that finished on 19 <sup>th</sup> May 2014. Initial feedback and analysis of the input (as at 7 <sup>th</sup> May) from stakeholders and members of the public is presented below. A further paper will be tabled at the Governing Body which will provide a more up to date appraisal of the outcomes of the consultation.
<b>Evidence in support of arguments:</b>	<p>The purpose of the Wiltshire dementia strategy (see Appendix 2) is to provide the strategic direction for Wiltshire Council and NHS Wiltshire Clinical Commissioning Group in supporting people with dementia and their carers over the next 7 years.</p> <p>A formal consultation process was held from 20 February to 19 May in order to seek feedback upon the proposed strategic direction from people who have experience of dementia, whether from personal or professional perspectives.</p> <p>Responses to the consultation survey at the time of submitting this report (7<sup>th</sup> May) indicate that people are supportive of the strategic direction that is being set and agree with the intentions of Wiltshire Council and NHS Wiltshire Clinical Commissioning Group. Responses at this point in time totalled 54 and answers to the closed survey questions may be found in Appendix 1. These responses need to be seen alongside the interaction and responses received at the 5</p>

events which were recently undertaken and included Trowbridge Area Board, Healthwatch event in Chippenham and Salisbury and Westbury Memory Café. An update will be provided on 20<sup>th</sup> May, which will reflect the responses for the whole period of the consultation.

In relation to the different elements of the strategy, there are some areas that respondents (as at 7<sup>th</sup> May) have highlighted as being of particular importance:

- Within the different stages of dementia, 24% believe that 'living well' is one of the most important stages, which supports the current and future focus of services, ie supporting people to remain well, independent and living at home for as long as possible.
- In terms of supporting groups of people who may not be as well served by current services as the wider population, responses indicate that the strategy should focus on people who live alone without family support (44%) and those people who live in rural areas and / or who do not have access to transport (24%). This is a challenge for all services, particularly given the rural nature of Wiltshire and further work is required to look at how improvements can be delivered innovatively within existing budgets.
- 18% of respondents felt that one of the most important priorities for health and social care was to ensure that health services have in place standard processes that allow for early identification, diagnosis and treatment of people with memory problems. This supports the work that has been taking place locally and nationally to raise awareness about dementia, encouraging people to seek a diagnosis and treatment if appropriate, as well as the investment in the dementia LES, DES and CQUINs.
- 15% of respondents felt that one of the most important priorities for health and social care was to review and modernise dementia related specialist services to ensure timely access to specialist memory assessments and treatment as required, as well as specialist support to other care services. This supports the clearing of the backlog of patients waiting to access specialist services and the referral to specialist assessment which is now 2 weeks (target is 4 weeks) and the referral to treatment which has a target of 13 weeks.

Respondents also highlighted as priorities the importance of ensuring that all public services are able to support people with dementia and their carers and family (21%) and ensuring that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard (27%). This echoes the strategic direction being taken which highlights that dementia is everyone's business and not just that of specialist care services. Whilst this is already being

	<p>addressed within health and social care services, there is significant work to ensure that it is embedded across all public services. Dementia friendly communities will go some way in supporting the delivery of this priority.</p> <p>In addition to the points above, a range of comments have been submitted as part of the consultation and these reflect other areas that people believe are of importance:</p> <ul style="list-style-type: none"> <li>• Early decision making whilst people have the capacity to contribute to the process</li> <li>• Supporting people who fund their own care</li> <li>• Supporting people to live active and fulfilling lives, including participation in their local community</li> <li>• Supporting people with health conditions in addition to their dementia e.g. learning disability, Parkinson's, hearing and sight impairments</li> <li>• Providing person centred care</li> <li>• Reducing the stigma associated with dementia</li> <li>• Improving quality of care, particularly within health services</li> <li>• Staff training</li> <li>• Listening to and involving family carers</li> <li>• Supporting people with dementia who do not recognise their needs and do not wish to accept support</li> <li>• Equitable services across the county</li> <li>• A broader range of services that are able to meet the needs of all people with dementia, irrelevant of the dementia an individual may have.</li> </ul> <p>Several responses indicated that people welcomed the strategy, although there were concerns raised about how it will be implemented and the costs associated with doing so. As detailed under the Financial Implications section, the implementation of the strategy will be undertaken within the existing budget. Work may be required to prioritise key workstreams.</p>
<p><b>Who has been involved/contributed:</b></p>	<p>In developing the strategy, work took place to engage with people with dementia and their carers and families in Wiltshire. This involved attending various forums and talking to people about their experiences of living with dementia in Wiltshire to identify what is important to them in their life with dementia, the areas that are working well and where service improvements are required. This engagement work formed the basis of the strategy. The Wiltshire Dementia Delivery Board has overseen this engagement process and has been active in the development of the strategy.</p> <p>The consultation process involved inviting general public, groups and organisations in Wiltshire who have an interest in dementia to participate by providing feedback on the draft strategy.</p>

	<p>All relevant stakeholders were informed and invited to participate with communications being circulated to the general public, people with dementia and their carers, health and social care organisations, area boards, councillors, voluntary and community organisations, Healthwatch, town and parish councils. Consultation packs were accessible online, in hard copy by request and as reference copies in all public libraries. In addition to this, presentations have been made to the Trowbridge and Corsham Area Boards, the Westbury Memory Cafe and Healthwatch coordinated two consultation events.</p> <p>Appendix 4 provides more detail on the engagement work that was undertaken in developing the strategy and throughout the consultation process.</p>
<b>Cross Reference to Strategic Objectives:</b>	<p>This draft strategy supports the four main outcomes of the Health and Wellbeing Strategy, including the dementia-themed ambitions set out in the action plan. It does this through placing an emphasis on the following:</p> <ul style="list-style-type: none"> <li>• Making dementia everyone’s business so that people can live well in supportive and inclusive communities.</li> <li>• Providing care and support to promote people’s independence, health and wellbeing and quality of life.</li> <li>• Delivering improvements to care and health services so that they are able to deliver quality services that meet the needs of people with dementia.</li> <li>• Wherever possible, supporting people within their own homes, with care and support being delivered as close as possible.</li> </ul>
<b>Engagement and Involvement:</b>	Please see “Who has been involved/contributed” section.
<b>Communications Issues:</b>	Communications are being undertaken jointly by NHS Wiltshire Clinical Commissioning Group and Wiltshire Council. There are no issues to report.
<b>Financial Implications:</b>	There has currently been no additional investment identified to deliver the dementia strategy as a whole. However, it is acknowledged that the population living with dementia in Wiltshire will increase by 28% by 2020. It is anticipated that unless additional funding is made available within the future, the delivery of the strategy will be achieved through using the current spend in an efficient and effective manner in order to meet the anticipated increase in demand.
<b>Review arrangements:</b>	Following the end of the consultation process (19 <sup>th</sup> May), the responses will be formally analysed and the draft strategy will be reviewed and amended as required. It will then proceed through the relevant governance channels in order to be formally agreed by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group. The Wiltshire Dementia Delivery Board will be responsible for overseeing the implementation and review of the strategy.
<b>Risk Management:</b>	The main risk associated with the dementia strategy is the increasing number of people living with dementia in Wiltshire and the related additional demand being placed upon services. The strategy

	<p>addresses this risk through a number of measures which focus upon maximising existing services and resources:</p> <ul style="list-style-type: none"> <li>• Dementia friendly communities that support people to live well with dementia and maintain their independence and wellbeing.</li> <li>• Working with non-specialist health and care services to ensure that they are trained and supported to meet the needs of people with dementia. They in turn can then provide support to the majority of people with dementia, with specialist services only being required at critical points in time.</li> <li>• Delivery of improvements in existing health led services such as acute hospital liaison services, memory services and primary care led diagnoses, treatment and advisory activities</li> </ul> <p>The risks associated with not implementing this strategy, include:</p> <ul style="list-style-type: none"> <li>• Placing the wellbeing, independence and safety of people with dementia and their carers and families at significant risk through a lack of suitable provision of care and support services.</li> <li>• An increased demand on health and social care services and budgets when people reach crisis due to a lack of preventative and early intervention services.</li> <li>• A failure of the statutory bodies within Wiltshire to respond to national guidance, policy and legislative duties.</li> </ul>
<b>National Policy/ Legislation:</b>	The key national policies include the Living well with dementia: a National Dementia Strategy (Department of Health, 2009) and Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015 (Department of Health, 2012).
<b>Equality &amp; Diversity:</b>	As part of the strategy, an equality analysis has been undertaken and is appended – see Appendix 3. This will be reviewed once the draft strategy has been through the formal consultation process.
<b>Other External Assessment:</b>	Prior to entering formal consultation, the draft strategy was agreed by Wiltshire Council Cabinet and NHS Wiltshire Clinical Commissioning Group Governing Body. It was also presented to the Health Select Committee on 14 <sup>th</sup> January 2014 and has been the subject of attention of the AWP / Dementia Task Group over recent months. A wide range of partners and stakeholders have been invited to review the strategy as part of the consultation process and submit responses on the document. In addition, an update on the consultation is being presented to the Health and Wellbeing Board on 22 <sup>nd</sup> May.
<b>What specific action re. the paper do you wish the Governing Body to take at the meeting?</b>	The Governing Body is asked to note the consultation process and initial draft responses on the basis that following formal analysis these will be used to review and amend the Wiltshire Dementia Strategy. The updated strategy and action plan will be presented for formal approval at the July Governing Body.

**Appendix 1 – Snap shot of responses to closed questions in the Dementia Strategy Consultation Survey (7<sup>th</sup> May 2014)**

<b>Q1. Stages of living with dementia. Which THREE of the following do you consider to be most important in dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	Reducing the risk of developing dementia	8
b.	Recognising memory problems	15
c.	Learning it's dementia	17
d.	Planning for the future	17
e.	Living well with dementia	24
f.	Managing at more difficult times	16
g.	Care at end of life	3

<b>Q2. Organisations will: Which FOUR of the following statements do you think is most important when dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	Promote the inclusion of people living with dementia in the community so dementia becomes everybody's business.	10
b.	Work together with partners to develop and deliver reliable, high quality and sustainable services that put the individual at the centre of delivery.	13
c.	Recognise and understand individuals, their identities, wishes and abilities.	9
d.	Promote health and wellbeing and support people to remain independent for as long as possible.	13
e.	Provide support and services to people with dementia and their carers in a compassionate, honest and equitable manner.	10
f.	Take a proactive approach to supporting people with dementia to live their lives to the full and to continue undertaking activities they enjoy.	10
g.	Listen to people and involve them in decision making so that they have control and influence over the care and support they receive.	12
h.	Treat people with respect and dignity.	7
i.	Improve services by listening to what people with dementia and their carers tell them about their experiences of receiving care and support.	16

<b>Q3. Making a difference. Which FOUR of the following statements do you think is most important when dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	I am encouraged and supported to have a healthy and active lifestyle.	6
b.	I was diagnosed early and with the correct medication and treatment package.	15
c.	I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.	10
d.	I get the care and support which are best for my dementia and my life.	20
e.	I am treated with dignity and respect.	12
f.	I know what I can do to help myself and who else can help me, especially in times of crisis.	8
g.	Those around me and looking after me are well supported.	15
h.	I can enjoy life.	8
i.	I feel part of a community and I'm inspired to give something back	4
j.	I am confident my end of life wishes will be respected.	4

<b>Q4. Groups of people living with dementia. Which TWO of the following groups do you think is most important when dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	People with early onset dementia (aged under 65 years old)	20
b.	People with learning disabilities and dementia	9
c.	People with dementia from black and minority ethnic communities	0
d.	People with dementia who live alone without family support	44
e.	People with rarer forms of dementia	3
f.	People who live in rural areas and / or who do not have access to transport	24

<b>Q5. Priorities for health and care services. Which FOUR of the following statements do you think is most important when dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	Make sure that health promotion activities are taking place to reduce the risk of people developing dementia.	4
b.	Make sure that health services have in place standard processes that allow for early identification, diagnosis and treat of people with memory problems.	18
c.	Monitor and review the dementia adviser service and make improvements as necessary.	5
d.	Promote and improve services for carers, including carers breaks	13
e.	Continue to improve and rollout care services so that people can be supported to remain independent and living at home.	17
f.	Develop new care homes and extra care schemes designed to meet the needs of people with dementia to meet future demand.	7
g.	Improve the quality of care in different settings including care homes.	10
h.	Review and modernise dementia related specialist mental health services to ensure timely access to specialist assessments and treatment as required, as well as specialist support to other care services.	15
i.	Improve dementia care in acute hospitals.	6
j.	Improve end of life care for people with dementia.	5

<b>Q6. Priorities for all public services (including health and social care) and communities. Which THREE of the following statements do you think is most important when dealing with dementia in Wiltshire?</b>		<b>% of responses</b>
a.	Raise awareness about dementia within the general public and mainstream services e.g. leisure and libraries.	10
b.	Undertake projects to better understand the needs of people with a dementia for whom services are less accessible so that improvements can be made e.g. learning disabilities, black and minority ethnic communities.	10
c.	Establish dementia friendly communities across Wiltshire.	17
d.	Make sure that all services are able to support people with dementia and their carers and family.	21
e.	Develop additional community therapeutic activities for people with dementia and their carers.	14
f.	Ensure that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard.	27



# **DRAFT Wiltshire Dementia Strategy**

## **2014 – 2021**

## Introduction

This strategy has been developed by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG) in conjunction with various local partners from the statutory and voluntary sector, as well as through talking to people with dementia and their carers and families about their experiences in Wiltshire (see appendix A).

The main purpose of the strategy is to ensure that people with dementia and their carers and families are able to live well and are supported to do so through being able to access the right services and support at the right time, whether that be from organisations or their local community.

However, it is recognised that minimising people's risk of developing dementia is also an important aspect of care for the population as a whole. Thus this strategy also highlights the links to other relevant strategies and health promotion activities and services that target the risk factors.

We want the message of this strategy to be that it is everybody's business to support people with dementia and their carers and families in Wiltshire and not just the reserve of specialist care services.

For this to happen we need to understand:

- where we are now
- where we want to be by 2021
- how we get there and what success will look like

This document will address each of the above points so that people can understand the commitments and priorities of Wiltshire Council, NHS Wiltshire Clinical Commissioning Group and other organisations that support people with dementia and their carers and families in Wiltshire.

The focus of this strategy is all people with dementia and their carers and families, right from the point that they have concerns about their memory through to the end of their lives. For clarity, several different phrases will be used within the document to describe different groups of people:

- People with dementia – People who have dementia (whether diagnosed or undiagnosed)
- Carers – People who provide unpaid support to people with dementia – they are normally family members, partners, friends or neighbours.
- Care workers - Care workers – Paid staff who support the person with dementia and their carer(s).

The word 'dementia' describes a group of symptoms that occur when the brain is affected by specific diseases and conditions, such as Alzheimer's disease and vascular dementia, amongst others. Symptoms of dementia vary but often include loss of memory, confusion and problems with speech and understanding. Dementia

is progressive and as it advances so do the symptoms, up to the point that people will have difficulty in undertaking everyday tasks and will need increasing support and assistance from others.

In Wiltshire dementia is seen as a long term condition, although it is acknowledged that many specialist dementia services are provided by a mental health organisation (Avon and Wiltshire Mental Health Partnership) and that people with dementia may also have needs relating to their mental health.

Whilst there is currently no cure for dementia, there are a number of types of support that can help someone to live well with dementia. Support and treatment can also often help to alleviate symptoms or to slow the progression of the dementia for many people.

## **Section 1: Where we are now**

### **National and local policy, legislation and guidance**

Within recent years there has been an increased focus on dementia at a national level due to a number of factors, including a rising older population and therefore increasing number of people with dementia coupled with a lack of awareness and understanding of dementia leading to stigmatisation and poor quality care.

As a result of this, there is now a substantial body of national policy, legislation and guidance that advises and directs organisations on how to best support people with dementia and their carers and families (see Appendix B for more detail). Amongst this there are two pieces of policy which are most relevant to this strategy:

#### **Living well with dementia: a National Dementia Strategy (Department of Health, 2009)**

The strategy focuses on driving improvements for people with dementia and their carers and families in three main areas:

- Awareness and understanding – Improved public and professional awareness and understanding of dementia and the stigma associated with it.
- Early diagnosis and ongoing support – Good quality early diagnosis and intervention; good quality information for those with diagnosed dementia and their carers; and easy access to care, support and advice following diagnosis and follow on medication management.
- Living well with dementia – High quality health and social care services so that people can live well with dementia until the end of their lives.

#### **Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015, (Department of Health, 2012)**

This aims to deliver a number of actions that focus on three main areas:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

Locally, the previous Wiltshire Dementia Strategy developed in 2009 has provided the context and direction for health and social care provision for people with dementia and their carers and families. However, many people with dementia and their carers will have needs that can be met by non-specialist services and/or have other needs that do not relate to their dementia e.g. housing, other long term conditions etc. There are a number of other local strategies (listed in Appendix B) which cover these areas and so this document should be read in conjunction with them.

## **People at risk of developing dementia**

Age is considered the highest risk factor for dementia, and the percentage and numbers of older people in the population is increasing. However, there are a high number of people who have modifiable risk factors for dementia who can be targeted.

In addition to age, risk factors for developing dementia include vascular disease such as cardio-vascular disease and stroke plus smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels (NICE, 2013). Those who have depression are also at higher risk of developing dementia. There are also those who have a genetic risk for dementia, though this area is not yet fully understood. There are people who will have more than one of these risk factors.

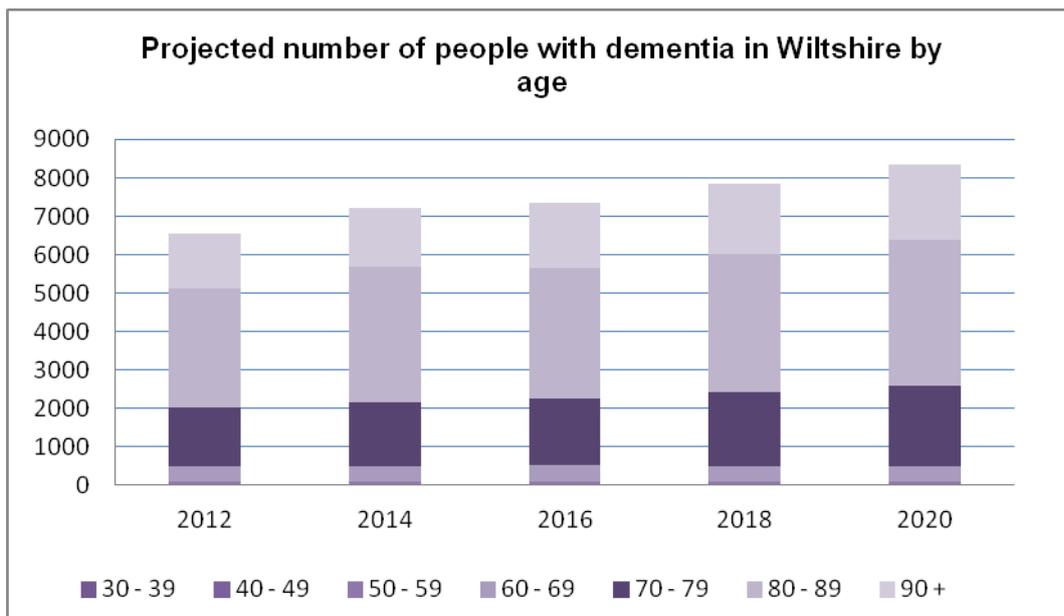
It has also been found that keeping one's mind active and also being socially active can also help reduce the risk of dementia. There is concern that due to the rural geography of Wiltshire, people are more likely to be socially isolated.

## **People with dementia and their carers and families in Wiltshire**

Wiltshire is a predominantly rural county and in 2011 had a total population of 470,981, 21.5% of whom were at retirement age (65+ years for men and 60+ years for women). This compares to 19.4% for the whole of England. This is significant because dementia is most common in the older population as its prevalence rises significantly with increasing age. One in three people over 65 will develop dementia, whilst a much smaller proportion of the population (about 1 in 1400) will be affected by early onset dementia which occurs in younger age groups.

It is difficult to give exact figures for the number of people with dementia within the population as reported rates differ widely depending on the criteria and study methods used.

According to figures produced by Oxford Brookes University and the Institute of Public Care (2013), the population of Wiltshire with dementia in 2012 was 6,538 and they estimate that this will increase by 27.8% in 2020 – this equates to an additional 1800 people with dementia. The age groups that will see the largest increases are 90 + years old (40% increase) and 70 – 79 years old (36% increase), whilst there will be a decrease of 12% in people aged 40 – 49 years old.



Information source: Projecting Older People Population Information System and Projecting Adult Needs and Service Information (Oxford Brookes University and Institute of Public Care, 2013)

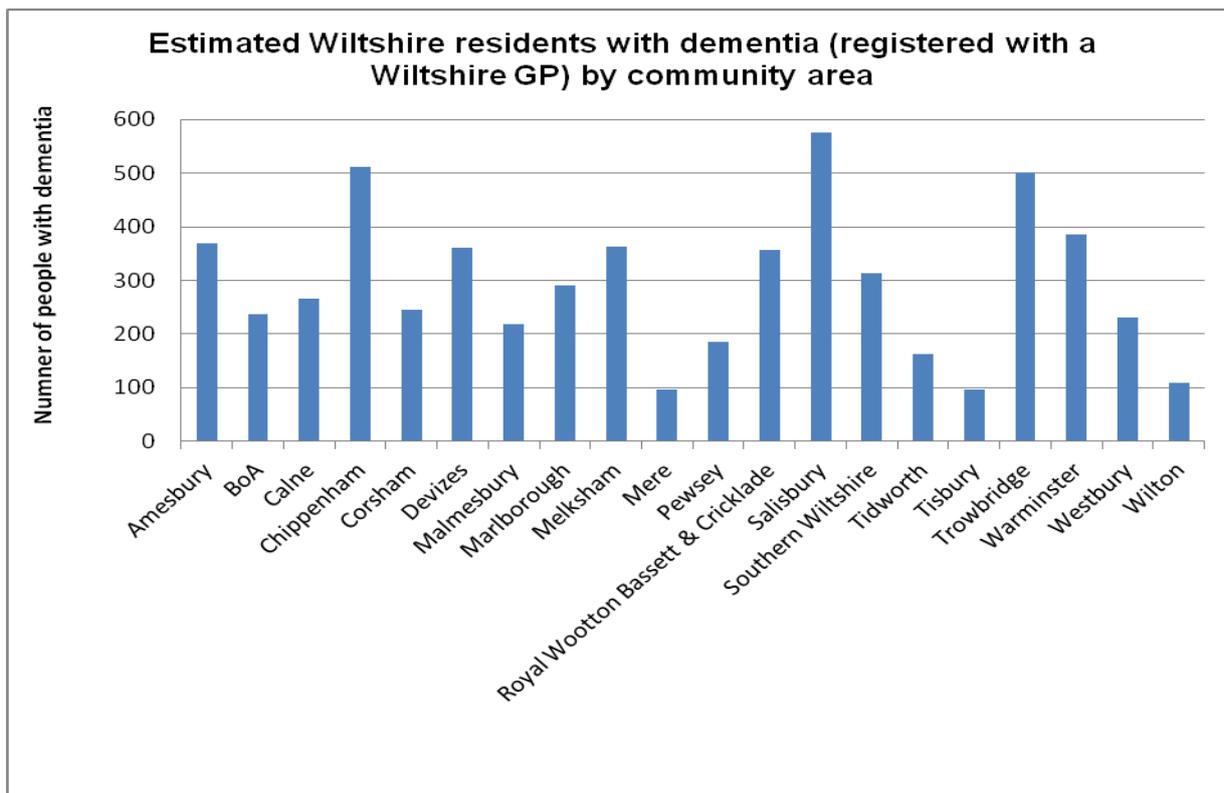
The NHS Commissioning Board and NHS South of England (2013) have also produced information about the population of Wiltshire with dementia through a tool called the Dementia Prevalence Calculator. This tells us that in 2013/14 there are an estimated 6,512 people with dementia in Wiltshire. Looking at the information in more detail we can get a better understanding of our local population (more detailed information can be found in Appendix C):

### Diagnosis

According to the Dementia Prevalence Calculator, the current diagnosis rate in Wiltshire is 37.4%. This is the number of people with dementia who have received a formal diagnosis which has been recorded by their GP. This means that 62.6% of the population who have a dementia do not have a diagnosis i.e. this is an unmet need. Nationally there is a drive to promote early and timely diagnosis to ensure that people can access the care and support they require, as well as being able to plan for their futures.

### Community areas

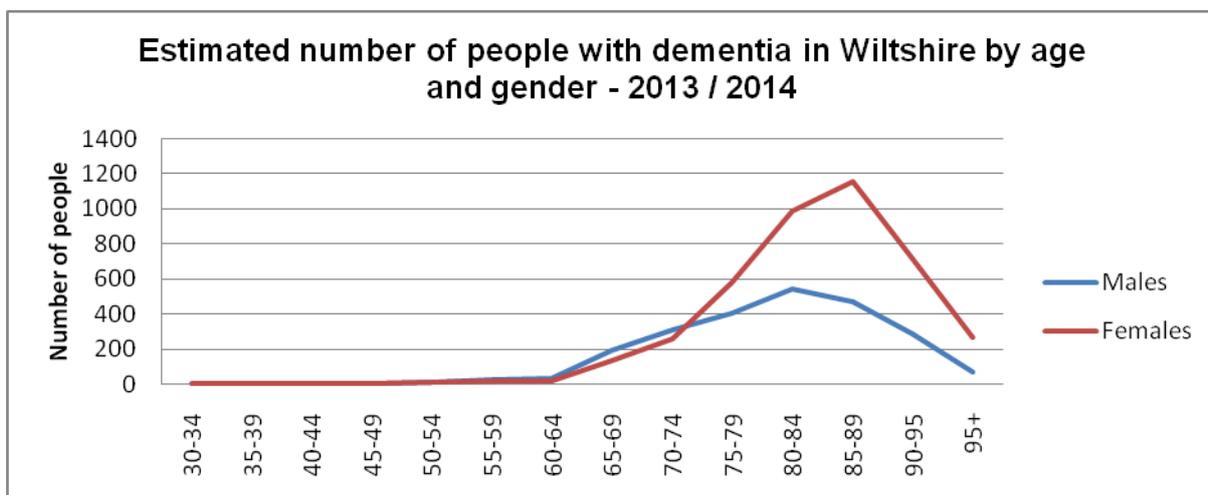
The following graph provides a picture of where Wiltshire residents who are registered with a Wiltshire GP surgery and have dementia live.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2012)

### Age and gender

In line with national figures the majority of people with dementia in Wiltshire are women (64%) whilst only 36% are men. However it is worth noting that of the 135 people who have early onset dementia (this is when the individual is under the age of 65 years old) 59% are male and 41% are female. This again reflects the national trend. Over 4,500 of people with dementia are aged 80 years of age or older, and of these 1,348 are 90 years or older.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2013)

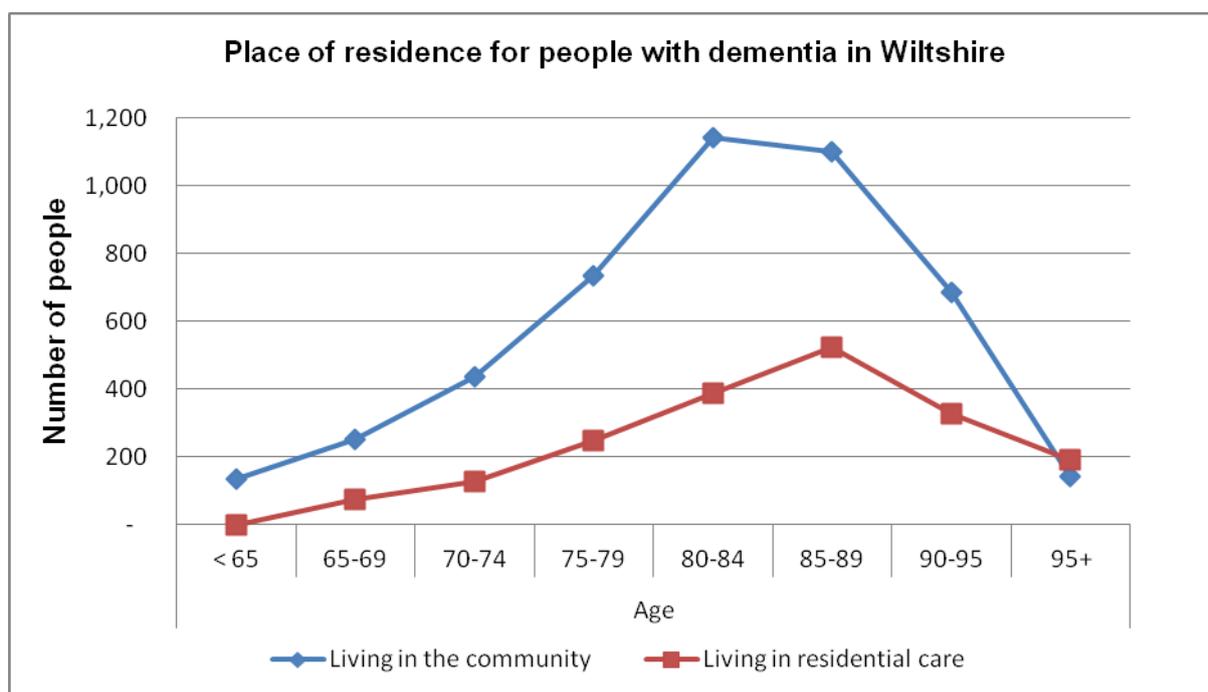
## Severity of dementia

Dementia is progressive, meaning that as time passes people's symptoms will increase and they will require more help and support to live well. It is recognised that there are three broad levels of dementia, which reflect the impact that the dementia has on the individual and their ability to care for themselves. In 2013, the Dementia Prevalence Calculator identified that of the population with dementia in Wiltshire:

- 55% have mild dementia
- 32% have moderate dementia
- 13% have severe dementia

## Place of residence

According to national statistics, 71% of people with dementia live within the community, whilst 29% in residential care. If applied to the Wiltshire population this equates to 4,629 people living in their own homes, whilst 1,899 live in residential care settings (residential and nursing care homes). Of those people who live in the community in their own home, Alzheimer's Society (2012) estimate that one third live alone.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2013)

## **End of Life**

The National End of Life Care Programme (2012) highlighted that in 2008 - 2010 in 18.3% of deaths in Wiltshire, the cause of death on the death certificate mentioned Alzheimer's, dementia and senility. This compared to the England average of 17.3%.

In Wiltshire this represented an average of 766 deaths per year and of these the place of death was as follows: 11% at home, 62% in a care home, 26% in a hospital and 0% in a hospice.

## **Carers**

In relation to the support provided by carers, according to figures produced by Alzheimer's Society (2012) it has been estimated that there are approximately 5,454 family members and friends acting as carers to people living with dementia in Wiltshire.

## **Other aspects of the Wiltshire population**

In relation to ethnicity and religion, there is no specific data about the population of Wiltshire who have dementia. However, we do have information from the 2011 Census which relates to the whole population. Whilst we need to take in to consideration that this may not be truly reflective of people with dementia, it would indicate that:

- The majority of people are White British (93%) followed by Other White (which mainly consists of European Accession countries, including Poland) and then Other Asian (which includes the Filipino and Polynesian communities).
- The majority of people are Christian, followed by having no religion or not wishing to state their religion.

It is important to remember that there are certain groups of people with dementia in Wiltshire that services may not be as well placed to meet the needs of when compared to the general population. However, it is equally as important to do so and work is needed to look at how this is best achieved. These groups include, but are not limited to:

- People with early onset dementia (are aged under 65 years old)
- People with learning disabilities and dementia
- People with dementia from black and minority ethnic communities
- People with dementia who live alone without family support
- People with rarer forms of dementia
- People who live in rural areas and / or lack transport

An equality analysis (Appendix H) provides more information.

## **Investment in services**

Using estimates from Knapp and Prince (2007) and the Dementia Prevalence Calculator, the annual financial cost of dementia in Wiltshire in 2013/14 is approximately £152 million. This includes accommodation, care provided by formal care agencies, as well as approximately £55 million from informal care by family and friends.

In 2013/14 NHS Wiltshire Clinical Commissioning Group project they will invest £7.5 million into supporting people with dementia, their carers and families. This sum includes memory services, the dementia Local Enhanced Service (LES), voluntary sector services, inpatient accommodation, community support and acute hospital liaison services.

During the same period, Wiltshire Council project they will spend £14.8 million supporting people with dementia and their carers and families. This sum includes commissioning specialist voluntary sector services and individual social care packages and placements where people have a recorded dementia that has been diagnosed.

There is also approximately £0.1million invested through a budget that contains pooled funding from Wiltshire Council and NHS Wiltshire Clinical Commissioning Group that is targeted at supporting carers of people with dementia.

In addition to the amounts identified above, it should be noted that many services funded by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group which people with dementia and their carers and families access are not specialist and so it has not been possible to include the associated costs within these figures. Examples include non-specialist carer support services, hospital care and community services for older people. In addition many people who have dementia do not have a formal diagnosis and so have not been included in the figures above.

In addition to this, there is a notable contribution from the voluntary sector with specialist dementia organisations bringing approximately £395,000 of fundraising in to the county in 2012/13. Alzheimer's Support also estimates that their unpaid volunteers give an average of 101 hours support each week. According to the formula recommended by Volunteering England, this volunteering activity is worth £1,324 per week or approximately £69,000 annually.

## **Current service provision in Wiltshire**

The services currently available to people with dementia and their carers and families have been delivered to date under the direction of the previous Wiltshire Dementia Strategy which was developed in 2009 and the Prime Minister's Challenge on Dementia (2012). Successes that have been delivered during this time can be found in Appendix E.

The Wiltshire Dementia Delivery Board has been responsible for mapping current service provision for people with dementia and their carers and families in Wiltshire. This exercise was undertaken in 2013 and the model of care developed by Dr Edana

Minghella (2012) was used as the framework (see Appendix D). This model of care identifies the following six phases that people are likely to experience when living with dementia:

- Recognising memory problems
- Learning it's dementia
- Planning for the future
- Living well with dementia
- Managing at more difficult times
- Care at end of life

Minghella identifies a range of proposed services within each of the above phases that should be in place if people are to receive the care that they may need when living with dementia. It was agreed that this was the desired model of care in Wiltshire and so was used as the basis for looking at the services that already exist in the county and where there were gaps or further improvements were required. A further phase of 'Reducing Risk' has also been added to cover the work taking place to promote health and wellbeing, and therefore reduce the risk factors within the general population associated with the development of dementia.

It was identified that many of the current services accessed by people with dementia and their carers and families are non-specialist services i.e. they support people with a range of needs. These services include support for carers, hospital care, Help to Live at Home etc.

There were also a number of current specialist services identified that are designed to specifically work with people with dementia and their carers and families and these include dementia community activities, the dementia adviser service, specialist mental health service etc.

In addition there are a number of services that support people to reduce their risk of developing dementia. These focus on reducing the risk of cardiovascular disease, stroke and diabetes and aim to reduce the levels of obesity, smoking, excessive alcohol use, cholesterol and mental health conditions such as depression.

These current services can be seen in the table below on page 12.

The Wiltshire Delivery Board also looked at where the gaps were in provision for people with dementia and their carers and families and where there could be improvements made to existing services in order to deliver better care and support. These gaps and improvements included support for specific groups of people with dementia (including people who live alone, people with early onset dementia and people with learning disabilities), advanced care planning and out of hours support during a crisis.

Appendix E provides more information about the services and gaps that were identified, as well as describing what current services look like.

Reducing risk	Recognising concerns	Learning it's dementia	Planning for the future	Living well with dementia	Managing at more difficult times	Care at end of life
NHS Health Checks ~ Wiltshire Stop Smoking Service ~ Wiltshire Substance Misuse Service ~ Active Health ~ Lift Psychology	Memory Service - Dementia assessment, diagnosis and treatment				GP out of hours service ~ Complex Intervention & Therapy Team	
	Primary care - Dementia assessment, diagnosis and treatment			Day services ~		
	Dementia CQUIN in acute hospitals		Life Story Groups (Alz Support) ~ Home improvement agency – part of Help to live at Home service (Equipment ICESS)	Specialist Home & Community Support Service ~ Movement for the Mind ~ Singing for the Brain ~ Active Health Programme ~ Counselling	Acute hospital liaison service ~	My Home Life programme in care homes ~ Continuing Health Care ~ Hospices
	Awareness raising activities and resources	RUH Community geriatrician			Acute hospitals ~ Inpatient assessment service ~ MH Care Home Liaison Service ~ Emergency Duty Service ~ STARR scheme ~ Extra Care Housing ~ Care homes ~ Respite	
				Social care ~ HTL@H ~ Telecare ~ DPs ~ Health community teams ~ Court of Protection		
	Support for people who fund their own care					
	Safeguarding ~ Primary care liaison service ~ Dementia Adviser Service ~ Memory cafes ~ Library resources ~ Support for carers (groups, training, assessments, breaks) ~ Advocacy ~ Good Neighbour Scheme ~ Wiltshire Citizens' Advice Bureau ~ Health Matters sessions					

## **What do people with dementia and their carers and families tell us?**

There is a large amount of research that has taken place at a national level that shares the experiences of people with dementia and their carers and families and much of this can be applied to Wiltshire.

However, in developing this strategy, work has taken place to meet with people with dementia and their carers and families in Wiltshire to find out what is important to them in relation to their lives with dementia and what their experiences of care and support services have been locally.

The things that people with dementia and their carers and families said are important to them and are going well include:

- Community activities such as memory cafes and Singing for the Brain
- Support from the voluntary sector
- Being able to meet and socialise with other people living with dementia
- Day care
- Telecare

The things that people told us are important to them and need improving include:

- Support for people living alone
- Support to plan for the future
- Direct payments
- Transport
- Support for carers
- Understanding of professionals of the challenges of living with dementia
- Processes, paperwork and the language used
- More time
- The general public's understanding of dementia
- Support from businesses
- Person centred care

There were some things that people with dementia and their carers and families told us are important to them, but people have had mixed experiences:

- Support from GPs
- Specialist mental health services
- Knowing where to go for information and help
- Carer involvement
- Acute hospitals
- Care in care homes

More detailed information about the experiences of people with dementia and their carers and families can be found in Appendix F.

## **Section 2: Where we want to be by 2021**

## **Ambition**

It is our ambition that all people with dementia and their carers and families in Wiltshire are treated as individuals and are able to access the right care and support, at the right time so that they can live well with dementia within supportive and understanding communities. This will be supported by providing care and support to promote people's independence, health and wellbeing and quality of life.

It is recognised that people will experience different phases of living with dementia, all of which are important, but which can differ vastly. In the model of care developed by Mingehlla (2012) these phases are as follows:

- Recognising memory problems
- Learning it's dementia
- Planning for the future
- Living well with dementia
- Managing at more difficult times
- Care at end of life

The strategy's ambition is equally applicable across all of these stages, as is the aim to minimise the number of times that people need to move within their life with dementia in order to receive the care they need, whether that be to a hospital, residential or nursing care home setting.

The ambition will be achieved by taking a proactive approach to supporting people to stay within their home and community wherever possible through the provision of care and support so that they can live well on a daily basis. At difficult times, such as crisis or illness, if people do need to travel to health or care services that cannot be delivered within their community, e.g. acute hospitals and/or specialist inpatient hospitals, this will be for as short a time as possible, with the aim to get the person back to their home as soon as possible.

Whilst it is acknowledged that there will be periods of time when people will require specialist dementia care services, it is the aim that people will be supported by generic, non-specialist care services for as long as possible and that these will be skilled and knowledgeable to appropriately support people with dementia and their carers and families.

In addition to this, it is the aim of this strategy to ensure that local communities are supportive, understanding and inclusive of people with dementia so that people can live well as active and valued members of our society. This will be achieved through implementing the concept of dementia friendly communities across Wiltshire.



This ambition and the following objectives, outcomes and principles will contribute to the service model that this strategy will deliver. In terms of delivery these elements will be structured across the phases of care identified by Minghella (2012) to form an action plan that organisations will sign up to (see Section 3 for more information).

With regard to reducing people’s risk of developing dementia, we will ensure that this strategy is linked in to the various other relevant strategies for risk factor reduction.

## Objectives

The objectives of the strategy are to:

- Keep up to date with the latest knowledge and research regarding dementia prevention, services and care and ensure these are integrated as appropriate into the initiatives and services provided
- Ensure that there are awareness raising resources within the community to support and encourage people to seek advice when they have concerns about their memory
- Ensure that there are processes in place across services to identify people who may have concerns about their memory
- Work with primary care and specialist health services to ensure that people are able to obtain a timely and quality assessment and diagnosis

- Ensure that following diagnosis, people (including those who fund their own care) are able to access good quality information and advice so that they can make informed and timely decisions and plan for their future
- Ensure that people have access to dementia community based services and activities that support them in their local communities
- Ensure people with dementia have access to appropriate specialist therapeutic services
- Ensure that people have access to peer support opportunities so that they can share their experiences and socialise with people in similar circumstances
- Support people to remain in their own home (whether that be a family home, extra care or residential care setting) for as long as possible through the provision of a range of care and support services
- Support people to remain independent for as long as possible through the use of telecare (assistive technology) and dementia friendly environments
- Ensure that there are a range of appropriate housing options for people with dementia, where their care needs can be met appropriately
- Ensure that carers are recognised and supported to care for as long as they are able and willing to do so through providing appropriate care and support.
- Work with local communities so that they are inclusive and supportive of people with dementia and their carers and families
- Ensure that there are good quality services in place that are able to appropriately support people with dementia and their carers at more difficult times in their lives e.g. access to specialist hospitals for assessment and treatment
- Ensure that people have access to support so that they are able to plan for end of life and have a good death
- Ensure that staff who work with people with dementia and their carers and families have the skills, knowledge and support to do so
- Ensure that people with dementia are encouraged and supported to make decisions and remain in control of their lives for as long as possible

## Outcomes

Wherever organisations, services and support may be involved in a person's life, by becoming signatories to this strategy, they are committing to improving services so that people with dementia and their carers and families in Wiltshire are able to agree with the following outcomes:

- I am encouraged and given the opportunity to have a healthy, active lifestyle.
- I was diagnosed early and with the correct medication and treatment package.
- I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia and my life.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me, especially in times of crisis.
- Those around me and looking after me are well supported.
- I can enjoy life.
- I feel part of a community and I'm inspired to give something back.
- I am confident my end of life wishes will be respected. I can expect a good death.

These outcomes were developed by the Department of Health (2010) for use by local areas to ensure that they are working to the standards in the National Dementia Strategy.

## Principles

All organisations are committed to ensuring that in the delivery of the services and support to people with dementia and their carers and families they will:

- Promote health, wellbeing and social inclusion.
- Work together with partners to develop and deliver reliable, high quality and sustainable services that put the individual at the centre of delivery.
- Be person centred and recognise and understand the individual and their identity, wishes and abilities.
- Enable people to maintain their independence and have freedom to live as they wish to do so for as long as possible and appropriate.
- Provide support and services to people with dementia and their carers and families that are compassionate, honest, accessible and equitable.
- Help to keep people safe from harm, whilst also taking a positive approach to risk.
- Listen to people with dementia and their carers and families and communicate with them effectively.
- Involve people with dementia and their carers in service delivery and recognise that involvement will look different for different people.
- Treat people with respect and dignity.
- Learn from their experiences of supporting people with dementia to inform future service improvements.
- Be flexible to the changing needs of people with dementia and their carers and families, whilst promoting continuity of care.

## **Section 3: How we get there and what success look like**

### **Priorities**

A number of areas have been identified as priorities for the initial period of this strategy. These include, but are not limited to:

#### **Reducing risk**

- To ensure that the strategy is linked to other relevant strategies involved in minimising people's risk of developing dementia, emphasise the dementia prevention aspect of their activities and that their outcomes are being achieved with any support that dementia services are able to provide.

#### **Recognising memory problems**

- Awareness raising within the general public and across mainstream services e.g. leisure and libraries.
- Ensure that health services, e.g. GPs and hospitals, have in place standard processes to identify, diagnose and treat people when they may have problems with their memory.

#### **Learning it's dementia**

- Monitor and review the delivery of timely and quality assessments by GPs and the memory service and make improvements as necessary.
- Undertake a research project to identify the understanding of dementia within black and minority ethnic communities and access to services in order to inform future service delivery.

#### **Planning for the future**

- Monitor and review the effectiveness of the dementia adviser service and their interface with other GP based services and make improvements as necessary.
- Commission a generic information portal linked to the Council's website and which will also be available in GP practices and libraries. Information included on the portal will include community services, universal services as well as registered services.

#### **Living well with dementia**

- Continue to work to promote and improve services for carers, including carers breaks
- Continued oversight and maintenance of treatment packages by general practitioners.
- Establish dementia friendly communities across Wiltshire.

- Work with mainstream care and health services, including Help to Live at Home, Neighbourhood Teams and GPs to ensure that they are able to appropriately support people with dementia and their carers and families.
- Work with public services, e.g. libraries and leisure, to ensure that they are able to appropriately support people with dementia and their carers and families to access their services.
- Further implement Help to Live at Home and its principles, including the delivery of initial support and outcome based care planning and delivery.
- Implement personal budgets and develop a personalisation policy.
- Develop links with the Community Campus programme.
- Develop community therapeutic activities.
- Develop new care homes delivering specialist dementia and nursing care.
- Support to improve the quality of care in different settings including care homes.
- Develop new extra care schemes, designed to meet the needs of people with dementia.

### **Managing at more difficult times**

- Work to shape and develop dementia related specialist mental health services to ensure timely access to specialist assessments and treatment as required, including the support they provide to other services e.g. care homes and hospitals.
- Ensure that all emergency / response / intermediate care services are skilled and knowledgeable about working with people with dementia
- Monitor and review progress within hospitals to deliver high quality dementia care in all relevant departments and disciplines.
- Analysis of triggers for people reaching crisis / requiring a move of home to receive appropriate care in order to inform future commissioning.

### **Care at end of life**

- Implementation of the End of Life Strategy, which will include people with dementia as a target group.

### **Overarching**

- Development of a needs assessment for people with learning disabilities and dementia to inform future service developments and commissioning.
- Development of a needs assessment for people with early onset dementia to inform future service developments and commissioning.
- Ensure that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard.

## **Action plan, measuring success and governance**

Supporting this strategy is an action plan that will be implemented (see Appendix H), which not only looks to address the priorities listed, but also the gaps identified within the mapping exercise and improvements required by people with dementia and their carers. This action plan will be accompanied by a set of success measures, which will be updated on an annual basis and overseen by the Wiltshire Dementia Delivery Board. The success measures will provide the Board with information to identify whether the implementation of the action plan has made a difference to people with dementia and their carers and families

The Wiltshire Dementia Delivery Board is a multi-agency board that is chaired by NHS Wiltshire Clinical Commissioning Group and consists of representatives from Wiltshire Council, health and social care organisations and the voluntary sector. It meets bi-monthly and is accountable to the Joint Commissioning Board.

Also in existence and with a role in delivering this strategy are the following groups:

- Carers Reference Group
- Wiltshire Alzheimer's Partnership Group
- Salisbury Foundation Trust Dementia Steering Group
- Transforming community services

## References

The following documents and information have been used in the development of this strategy:

Alzheimer's Society (2012) Dementia 2012: A National Challenge

Department of Health (2009) Living well with dementia: a National Dementia Strategy

Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015

Knapp, Martin and Prince, Martin (2007) Dementia UK. Published by Alzheimer's Society

Minghella, Dr Edana (2012) Transforming models of care for people living with dementia: Improving experiences and outcomes for people with dementia and their carers and families

National End of Life Care Programme (2012) National End of Life Care Profiles for Local Authorities: Wiltshire. Published by National End of Life Care Intelligence Network

NHS Commissioning Board and NHS South of England (2013) Dementia Prevalence Calculator - [www.dementiaprevalencecalculator.org.uk/](http://www.dementiaprevalencecalculator.org.uk/)

NICE (2013), Dementia Pathway Overview, <http://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-risk-factors-and-prevention>

Our Health South West (2013) Dementia Care [www.ourhealth.southwest.nhs.uk/service-data/indicator/diagnosis-rate.html?id=12253](http://www.ourhealth.southwest.nhs.uk/service-data/indicator/diagnosis-rate.html?id=12253)

Oxford Brookes University and Institute of Public Care (2013) Projecting Older People Population Information System - [www.poppi.org.uk/](http://www.poppi.org.uk/)

Oxford Brookes University and Institute of Public Care (2013) Projecting Adult Needs and Service Information - [www.pansi.org.uk](http://www.pansi.org.uk)

Wiltshire Council (2012) Wiltshire's diverse communities: Results from the Census 2011

Wiltshire Council (2013) Wiltshire Census 2011- Selected Statistics Profile Tool: Wiltshire Unitary Authority

## APPENDIX 3 - EQUALITY ANALYSIS

<b>Name of Service/Policy/Project/Decision to undergo Equality Analysis:</b>
Wiltshire Dementia Strategy
<b>Key contact person &amp; others involved:</b> Key contacts: Rhian Bennett (Commissioning & Contract Lead – Dementia, Wiltshire Council) & Susan Dark (Dementia Lead, Wiltshire Clinical Commissioning Group) Partners involved: Wiltshire Dementia Delivery Board
<b>Date Completed:</b> 19 <sup>th</sup> November 2013
<b>Review date (at least annually):</b> May 2014 – following the formal consultation process of the draft dementia strategy
<b>Identify aims:</b>
<p>The aim of the strategy is to ensure that all people with dementia and their carers and families in Wiltshire are treated as individuals and are able to access the right care and support, at the right time so that they can live well with dementia within supportive and understanding communities. This will be supported by providing care and support to promote people's independence, health and wellbeing and quality of life.</p> <p>It is recognised that people will experience different phases of living with dementia, all of which are important, but which can differ vastly. These are as follows:</p> <ul style="list-style-type: none"> <li>• Recognising memory problems</li> <li>• Learning it's dementia</li> <li>• Planning for the future</li> <li>• Living well with dementia</li> <li>• Managing at more difficult times</li> <li>• Care at end of life</li> </ul> <p>The strategy's ambition is equally applicable across all of these stages, as is the aim to minimise the number of times that people need to move within their life with dementia in order to receive the care they need, whether that be to a hospital, residential or nursing care home setting.</p> <p>Whilst it is acknowledged that there will be periods of time when people will require specialist care dementia services, it is the aim that people will be supported by generic, non-specialist care services for as long as possible and that these will be skilled and knowledgeable to appropriately support people with dementia and their carers and families.</p> <p>In addition to this, it is the aim of this strategy to ensure that local communities are supportive, understanding and inclusive of people with dementia so that people can live well as active and valued members of our society. This will be achieved through implementing the concept of dementia friendly communities across Wiltshire.</p>
<b>Collect and use evidence:</b>
<p>The strategy includes a range of information about the population of Wiltshire living with dementia. The majority of this has been developed by applying national statistics to the Wiltshire population and includes:</p> <ul style="list-style-type: none"> <li>• Prevalence and diagnosis rates</li> <li>• Severity of dementia</li> <li>• Place of residence</li> <li>• End of life</li> <li>• Age and sex</li> <li>• Distribution of the population by community area</li> </ul>

- Ethnicity
- Religion / faith
- Carers

In relation to gaps in the knowledge, these include:

- Disability
- Sexual orientation
- Marriage and civil partnership

Further work is required to look at these gaps in more depth although it is likely that in many cases national statistics would be applied to the Wiltshire population. In relation to disabilities it is acknowledged that certain conditions and illnesses increase people's risk of developing dementia. This is to be addressed through the action plan of the dementia strategy, which will include the commitment to undertake a needs assessment for people with learning disabilities and dementia. This will be overseen by the Wiltshire Dementia Delivery Board which will ensure that all relevant partners and stakeholders are involved as appropriate.

Further work is also required to look at whether the people accessing services are representative of the population with dementia. This will need to be addressed through commissioning and contract monitoring arrangements.

### Assess the impact:

It is the intention that the individuals that will benefit from the dementia strategy include all people who have dementia and their carers (people who provide unpaid care and support) and family members.

However there are certain groups of people with dementia for whom services have been less successful in reaching. These include:

- People with early onset dementia (are aged under 65 years old) – Due to age being a determining factor in the onset of dementia, it is noted that the majority of services for people with dementia are accessed by people who are in their 70s, 80s and 90s. It has therefore been identified that the small number of people (approx. 135 people) with early onset dementia may not feel that these services are appropriate for them. In addition the challenges that someone with early onset dementia may face are likely to be different to an older person, including employment, children and the misconception that dementia only affects older people. At present there are no services commissioned specifically for this group of individuals.
- People with learning disabilities and dementia – It has been identified that people with a learning disability, and particularly Down's Syndrome, are at higher risk than the general population of developing a dementia. In addition the assessment and diagnosis process can often be more difficult and so people may not receive a timely diagnosis and without this may not be supported appropriately to live well. However in Wiltshire little work has been undertaken to raise awareness of this or to better understand the needs of this group of people.
- People with dementia from black and minority ethnic communities – Studies at a national level have identified that further work is required across the country to better support people from BAME communities who have dementia. Within different BAME communities and cultures there are varying degrees of understanding and awareness of dementia, as well as attitudes towards caring and family duties. These can often prevent people from accessing advice and support in a timely manner. In addition health and care services are often not proactive in engaging with BAME communities or supporting people with dementia in a way that is appropriate.
- People with dementia who live alone without family support – It has been acknowledged by all stakeholders in Wiltshire that supporting people who live alone can be particularly

difficult and often results in people not accessing services until they reach crisis. This can be exacerbated when people with dementia may not be aware that they are unwell and require care and support. At present no work has been undertaken to target this specific issue.

- Couples where both individuals have dementia – On a similar note to people who live alone without support, it can also be difficult to support couples who live in their own home and both of whom have dementia.
- People who live in rural areas and those who lack transport – With Wiltshire being a predominantly rural county, people with dementia and their carers have raised concerns about transport and the difficulty in accessing services. These difficulties can often result in people not being able to access services that people who live in towns or who have access to transport can.

It has been acknowledged that from a commissioning perspective there is work to be done to better understand the needs of the above groups and how they could best be met. This work is being addressed through a number of actions within the strategy action plan which will include:

- Undertaking a number of needs assessments, including for people living alone, people with learning disabilities and people with early onset dementia.
- Developing a working group focusing upon transport issues and possible solutions
- Undertaking a project that will engage with the BAME population to identify their awareness and understanding of dementia, as well as the services that they access.

In addition to identifying areas for improvement, it is widely considered that if you get services right for people with dementia then they will be right for most people i.e. others will benefit from the improvements implemented specifically for people with dementia. In relation to the dementia strategy actions delivering these wider benefits include the following:

- The development of dementia friendly communities
- Improving the workforces understanding of dementia
- Dementia friendly environments

### **Ensure fairness:**

The implementation of the dementia strategy is a priority as it has been identified that there is an increasing number of people with dementia in Wiltshire – by 2020 there will be a 28% increase. Not only is this affecting individuals, families and communities, but is also placing an increasing pressure upon health and care services. It is also acknowledged that people with dementia and their carers often receive care that is of variable quality and / or does not meet their needs appropriately. This is often because of a lack of understanding about dementia, systems not being flexible to making the adjustments that people with dementia require, and dementia still being a stigma for many people.

At a national level quality of life outcomes for people with dementia are often lower than for the general population. For example:

- Isolation caused by loss of social networks ability to access community activities etc
- Reduced life expectancy
- Stigmatisation of dementia and lack of public understanding

The strategy aims to improve the equity between people with dementia and the general

population. This will ensure that people with dementia have an improved quality of life and are able to achieve the same outcomes in life as those without dementia. It has not been identified as excluding any particular groups, although work is required to ensure that all groups can equally benefit.

#### **Finalise your decision:**

The draft strategy has been developed through engaging with stakeholders and people living with dementia in Wiltshire.

Wiltshire Council and Wiltshire Clinical Commissioning Group have been engaging with people with dementia and their carers and family a various forums across Wiltshire. Discussions focused around identifying what is important to people in terms of living with dementia, what is working well and what could be improved.

The Wiltshire Dementia Delivery Board has overseen this engagement process and has been active in the development of the strategy. This includes representatives from the Wiltshire Council, NHS Wiltshire Clinical Commissioning Group, the Avon and Wiltshire Mental Health Partnership, Alzheimer's organisations, Carer Support Wiltshire, Wiltshire and Swindon Users Network, SWAN Advocacy, the three acute hospitals, hospices and GWH community services. They agreed the draft strategy on 19<sup>th</sup> November 2013.

In addition the draft strategy is being presented to the CCG Executive on 2<sup>nd</sup> December, CCG Clinical Executive on 10<sup>th</sup> December and Joint Commissioning Board (JCB) on 12<sup>th</sup> December for approval. The JCB will approve the draft strategy before it goes to formal consultation.

This formal consultation process will last for three months and give people the opportunity to comment of the draft strategy. It will be placed upon the Wiltshire Council website, will be sent to partners for distribution amongst their customers, staff and partners and a press release will also be developed to ensure that people who may not be contact with services can contribute.

#### **Communicate what has happened:**

People with dementia and their carers and families have been informed of the development of the strategy through the engagement sessions, as well as inclusion of an article in the Alzheimer's Support summer newsletter. Organisational partners have been informed through the Wiltshire Dementia Delivery Board.

When the draft strategy goes to formal consultation, various methods will be used to inform people and provide them with the opportunity to contribute.

#### **Review your decision:**

The draft strategy will be reviewed following the end of the formal consultation process, which will last three months, as will this equality analysis.

#### Appendix 4 – Engagement work in developing the strategy and throughout the consultation process

Activity	Forum	Date	Detail
Engagement work with people with dementia and carers to inform strategy development.	Singing for the Brain	10 <sup>th</sup> September 2013	Questions were asked to identify a) What is important to people in their lives with dementia b) What is working well c) What could be improved
	Memory Café, Melksham	16 <sup>th</sup> September 2013	
	Singing for the Brain, Salisbury	September 2013	
	Movement for the Mind, Melksham	25 <sup>th</sup> September 2013	
	Carers Support Group, Devizes	27 <sup>th</sup> September 2013	
	Carers Support Group	1 <sup>st</sup> October 2013	
	Carers Reference Group, Melksham	16 <sup>th</sup> October 2013	
	Carers Focus Group, Trowbridge	21 <sup>st</sup> October 2013	
	3Ms memory group, Royal Wootton Bassett	1 <sup>st</sup> November 2013	
Engagement with stakeholder organisations to inform the strategy development and to seek approval to proceed to consultation	Wiltshire Dementia Delivery Board	2 <sup>nd</sup> July 2013	Mapping and gapping exercise of all services with strategic partners
	Wiltshire Dementia Delivery Board	3 <sup>rd</sup> September 2013	Discussion with strategic partners to agree engagement mechanisms with people with dementia and carers
	Dementia Topic Leads Meeting	30 <sup>th</sup> October 2013	Discussion to identify key issues when supporting people living with dementia.
	Wiltshire Dementia Delivery Board	19 <sup>th</sup> November 2013	First draft of strategy presented to the board
	Health Select Committee	14 <sup>th</sup> January 2014	Final draft presented
	Wiltshire Council Cabinet	21 <sup>st</sup> January 2014	Agreement obtained for draft strategy to proceed to consultation

	Wiltshire Dementia Delivery Board	21 <sup>st</sup> January 2014	Final draft of strategy and consultation plans presented to Board
	CCG Governing Body	28 <sup>th</sup> January 2014	Agreement obtained for draft strategy to proceed to consultation
Engagement during consultation period	Launch of consultation	20 <sup>th</sup> February 2014	Communications to all stakeholders including VCS, health and social care providers, press, community groups, area boards, town and parish councils. Documents made available online, in paper format and in libraries. Posters displayed in various settings including hospitals, libraries and GP surgeries. Articles about the consultation have been placed in various forums including the local press, VCS and community area websites, VCS newsletters etc.
	Corsham Area Board	20 <sup>th</sup> March 2014	Presentation on draft dementia strategy
	Wiltshire Dementia Delivery Board	20 <sup>th</sup> March 2014	Update on consultation provided to the Board
	Trowbridge Area Board	27 <sup>th</sup> March 2014	Presentation on draft dementia strategy
	Wiltshire Dementia Delivery Board	6 <sup>th</sup> May 2014	Update on consultation provided to the Board

	Westbury Memory Café	8th May 2014	Presentation and discussion on draft dementia strategy
	Healthwatch consultation event, Chippenham	12 <sup>th</sup> May 2014	Public meeting to discuss the strategy
	Healthwatch consultation event, Salisbury	13 <sup>th</sup> May 2014	Public meeting to discuss the strategy